

Experiencing heart transplantation: the patients' perspective

Os significados de ter o coração transplantado: a experiência dos pacientes

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RBCCV 44205-834

Abstract

Objective: For patients with heart failure, heart transplantation represents the possibility of survival and improvement in their quality of life. Thus, the awareness and participation of patients in the follow-up work by the healthcare team after transplantation are important. This study aimed at understanding the experience of heart transplantation based on the descriptions of patients.

Method: Twenty male and six female patients, whose ages ranged from 13 to 71 years old, were interviewed. The similarities of their accounts illustrated shared feelings which described their experiences.

Results: The patients re-experienced the transplantation phases and compared heart failure symptoms with the improvement achieved after transplantation. Some felt healthy whereas others reported the persistence of rejection and complications as well as the onset of other pathologies. However, all of them noted the improvement in their quality of life. Each one brought his own views concerning the experience itself, their relatives and the professionals who participated in their experience. They expressed their expectations regarding work and family achievements.

Conclusion: The contribution of this descriptive study lies in unveiling new perspectives of understanding such

patients' needs, thus helping professionals who assist them to respond more effectively to their individual necessities.

Descriptors: Heart transplantation. Quality of life. Adaptation, psychological.

Resumo

Introdução: O transplante cardíaco representa, para pacientes com falência cardíaca, a possibilidade de sobrevivência e melhorias na qualidade de vida. Para tanto, faz-se necessária a conscientização e a participação do paciente no trabalho de acompanhamento da equipe de saúde, pós-transplante. O objetivo do estudo foi compreender a experiência do transplante cardíaco, partindo da descrição dos pacientes.

Método: Foram entrevistados 26 pacientes, 20 homens e seis mulheres, entre 13 e 71 anos. As convergências dos depoimentos levaram às verdades gerais, que descrevem a experiência vivida.

Resultados: Os participantes revivem as fases do transplante. Comparam sintomas da falência cardíaca com os progressos que conseguiram após transplante. Alguns se sentem saudáveis. Outros relatam persistência da rejeição e complicações; e surgimento de outras afecções. Porém, todos

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Article received in December, 2005
Article accepted in August, 2006

comemoram a melhoria na qualidade de vida. Cada um traz sua visão particular sobre o vivido, sobre familiares e profissionais que compartilham a experiência. Expressam-se sobre suas expectativas de realização, no trabalho e na família.

Conclusões: A contribuição deste estudo descritivo reside em desvelar novas perspectivas para a compreensão das

necessidades deste paciente, capacitando os profissionais que os acompanham a responder mais efetivamente às suas necessidades individuais.

Descritores: Transplante de coração. Qualidade de vida. Adaptação psicológica.

INTRODUCTION

The frequent success of heart transplantation seen with the increase in survival rates and quality of life of transplant patients [1-3], identifies this type of therapy as the first choice for refractory heart failure which in Brazil has reached epidemic proportions [4]. The success of the procedure signifies not only a guarantee of survival for patients in end-phase heart disease, but gives them a greater degree of physical activity and quality of life [5-7]. Brazilian research suggests a necessity for consistent post-transplant professional support and education on self-care for recipients [8,9].

Studies on the quality of life after transplantation have compared the quality of life of patients before and after heart transplant (HT), showing improvement of the symptoms and excellent physical performance, although there is a deterioration in the financial and emotional conditions over some periods [5-7,10-12]. Among these studies, quantitative approaches predominate; few use a qualitative approach. As an example of this, Kaba et al. [13] interviewed 42 heart recipients, investigating the reactions and behavior to adapt to changes after HT, utilizing a descriptive and interpretive approach. Moreover Kaba [14] interviewed 11 American heart recipients, aiming at describing the problems faced by them in respect to medications and psychological and social conflicts.

No phenomenologic studies investigating the subjective experience of heart recipients were discovered using this approach but there is one relevant study by Wise [15] on liver transplantation recipients: nine children from 7 to 15 years old were interviewed at least one year after the procedure revealing the perception of these children about their experiences and providing important results to assist them. We believe that qualitative research on the perception of the patient in respect to what happened in the transplantation process, may offer important help to understand the necessities from the patients' point of view. Thus, the objective of this study was to investigate the experiences of HT patients aiming at trying to understand the significances that they attribute to the experience.

METHOD

The study was performed from a phenomenologic approach. The proposal of phenomenology is to study the experiences of individuals from the perspective of the people involved. Starting from descriptions of the heart recipients about how they lived through a HT, the researchers tried to analyze and understand the meanings that they attributed to their experience in a manner to discover convergent meanings and empirical variations subjacent to this experience [16].

Twenty-six heart recipients were interviewed (Table 1), in the period from March 2003 to March 2004, during routine consultations. As there were no studies subjectively reporting the experiences of heart transplantation recipients, in this study we selected patients with the most diverse characteristics (gender, age, time after HT, origin, occupation), in an attempt to find the most diverse perspectives of the participants to obtain a greater understanding of the phenomenon. Within the objectives of researchers there is no pretension to analyze these variables which have been the subject of quantitative research studies.

The participants were individually interviewed, using a single question: "How do you yourself see the experience of undergoing heart transplantation?" The descriptions of these patients on the experience were analyzed using phenomenologic procedures following the steps described by Sadala & Adorno [16]:

1. Individual analysis of the interviews (ideographic analysis), following the stages: careful reading of the interview aiming at understanding it as a whole; selection of the parts of the interview, called units of significance, that answer the question being studied; analysis and comprehension of these units of significance transforming them into the language of the researchers with a focus on the investigated phenomena; interpretation of the interview as a whole in the understanding of the researchers.

2. A look for convergences of all the interviews (Nomotetic analysis). The convergences were classified as

themes and analyzed from the perspective of the researchers, to identify general truths of the studied phenomenon from the perspective of the study participants.

The study was approved by the Research Ethics Committee of the institution where it was developed and participants signed informed written consent forms.

Table 1. Description of the study participants

Participants	Age	Gender	Origin	Profession	Year of HT
1	43	male	São Paulo	salesman	1994
P2	41	male	Cotia	retired	1996
P3	60	male	Diadema	waiter	1990
P4	49	male	São Bernardo	Project writer	1992
P5	55	male	São Paulo	retired	1998
P6	42	Female	Taboão da Serra	housewife	1994
P7	44	Female	São Paulo	housewife	2000
P8	35	male	São Paulo	Driver	2001
P9	38	Female	São Paulo	salesman	1999
P10	44	male	Guarulhos	retired	2003
P11	55	male	São Paulo	salesman	1999
P12	32	male	São Paulo	retired	1999
P13	65	male	São Paulo	Tool maker	1990
P14	57	male	São Paulo	retired	1990
P15	57	male	São Paulo	Businessman	2000
P16	71	male	São Paulo	retired	1998
P17	32	Female	São Bernardo	Student	2002
P18	69	male	São Paulo	retired	2001
P19	50	male	Limeira	retired	1992
P20	48	male	São Paulo	retired	1998
P21	17	Female	Piracicaba	Student	1994
P22	17	Female	Bebedouro	Student	1994
P23	13	male	Mogi das Cruzes	Student	2000
P24	17	male	São Paulo	Student	2002
P26	37	male	Ibaté	salesman	2000

HT – Heart Transplant

“Look, before transplantation I really suffered. I had a respiratory problem for four years. I really suffered. Four terrible years. Unable to breath, to sleep, I could not sleep...It was terrible. For four years I suffered very much. After transplantation my life changed completely. I breathe normally, I feel well and do everything normally. Everything I do during the day I do normally, a common person. There is nothing new. And I am very well. (pause). ...it is now nearly four years I feel well, really well. What can I say is this (pause). My life did not change at all... only... changed, changed for the better, of course, I was suffering very much. Now... now no, now I am well, for four years now, I live as a normal person, I do everything and eat anything (reinforces with tone of voice), although there are many things that I should not eat, but I eat. Many things that I should not eat, but I eat. And thank God all is OK. (As he stopped I asked again what these occurrences signified for him). Changed, changed for the better, of course, everything changed. Now I am well, I do everything normally, all normal, my life is normal. No nothing changed, only for the better. As before I could not do anything. I could not walk, I could not sleep, I could not do anything... four years that I suffered very much. After the transplantation thank God I am a normal person today. I do not feel tired anymore... nothing more... Most people are transplanted due to Chagas disease, but me no, I had a problem in the heart, heating of the left nerve of the heart, and so when I was admitted to hospital the doctor said that there was no other solution except transplantation. And thank God I managed a heart and today I am well. I feel well. My life is wonderful. (laughs) Better impossible. I can only be thankful for what happen to me because at that time never, I never though I would live with the organ of another person. I do not believe this, I only believe because it happened to me, I am alive with the organ of another person. But... apart from this... (lowers his tone of voice) everything is well. (He stopped to talk and I turned off the recorder. Later he spontaneously started talking again about the transplantation. I asked permission to record again) I, at the time of the transplant was 51 years old. And I received the heart of a youth of 18. That is, of course... I became young again. (laughs). Look, generally everyone who does a surgery like this has a little rejection, always has. But in my case there was no rejection whatsoever! How fantastic! I never saw something like this. The person... removed the heart of a guy and puts in me and it gives no problems whatsoever... none, none... look! Impressive! I find it hard to believe. Everyone jokes saying ‘God! Now you are 51 years old but like an 18-year-old!’ (laughs) Today I am 22 years old, aren't I? When I have lived another 50 years, I will be one hundred years old or so! And another thing, generally they say that people after transplantation are never well with the life, but I am very well with life, very well... I only have advantages... I feel so well. I mean to say, I do everything, and so I can not complain about life (laughs). Well, as I said to you, I ... don't have nothing new, that's it.

Fig. 1 – Description. Interview of participant 11, responding the question: “How do you yourself see the experience of undergoing heart transplantation?”

Table 2. Ideographic analysis: individual analysis of the interview of patient 11

Meaning unit (participant's language)	First elucidation	Researcher language	Meaning unit (phenomenon focus)
1. Look, before transplantation I really suffered. I had a respiratory problem for four years. I really suffered. Four terrible years. Unable to breath, to sleep, I could not sleep...It was terrible.	Respiratory problems: severe heart insufficiency causes dyspnea even at rest making physical activities impossible.	1. During 4 years the patient suffered with dyspnea due to heart insufficiency	11.1 Advanced heart insufficiency causes intense suffering and physical handicaps
2. After transplantation my life changed completely. I breathe normally, I feel well and do everything normally. Everything I do during the day I do normally, a common person. And I am very well.	Common person: in the context healthy person Normal person: within regular standards: within normality and sanity... (Borba, 2002)	2. After the transplant the respiration normalized, as did the daily activities.	11.2 HT promotes restoration of the well-being and physical capacity.
3. changed, changed for the better, of course, I was suffering very much. Now... now no, now I am well, for four years now, I live as a normal person, I do everything and eat anything	The post-HT patients are directed to follow a low-salt and low-fat diet	3. Live as a healthy person after the HT.	11.3 The recipient feels he acquires health again.
4. although there are many things that I should not eat, but I eat. Many things that I should not eat, but I eat. And thank God all is OK.	Problem of hearing of nerve and of the heart: the patient confuses relative symptoms to electro-cardiac impulses as the cause of the disease.	4. Does not rigorously follow the diet, but is well.	11.4 compliance to treatment after HT is not always complete (This meaning unit coincides with 11.3)
5. before I could not do anything. I could not walk, I could not sleep, I could not do anything...	Managed a heart: The patient refers to the process of inscription on the waiting list.	5. Before the HT he felt incapacitated.	11.5 The recipient equivocally shows he is informed about the cause of the heart disease that led to HT
6. four years that I suffered very much. After the transplantation thank God I am a normal person today. I do not feel tired anymore... nothing more...		6. Today I am a healthy person.	11.6 The recipient feels thankful for the chance to continue alive.
7. Most people are transplanted due to Chagas disease, but me no, I had a problem in the heart, heating of the left nerve of the heart, and so when I was admitted to hospital the doctor said that there was no other solution except transplantation.	Rejection: rejection is still the greatest cause of death after HT – 20% in the immediate postoperative period and 25% later (Bacal et al. 2000)	7. The patient confuses the symptoms that he feels (consequence of the disease) as the cause of HT.	11.7 It is difficult to believe that you can still live with a heart that is not yours.
8. And thank God I managed a heart and today I am well. I feel well. My life is wonderful. (laughs) Better impossible.		8. He is well thanks to finding a donor.	11.8 There are fantasies in respect to the influence of the donor on possible transformations that occur in the recipient.
9. I can only be thankful for what happen to me because at that time never, I never though I would live with the organ of another person.	The patient compares his chronological age that that of the donor.	9. He feels thankful. Did not think it possible to live with the organ of another.	11.9 The success of HT makes the recipient feel victorious and special.
10. I, at the time of the transplant was 51 years old. And I received the heart of a youth of 18. That is, of course... I became young again.	Well with life: in harmony with life, in peace (Borba, 2002)	10. Received the heart of an 18-year-old. He feels younger.	(This meaning unit coincides with 11.8)
11. Look, generally everyone who does a surgery like this has a little rejection, always has. But in my case there was no rejection whatsoever! How fantastic!	Does everything: in the context, capacity to do everyday activities	11. He considers the privilege of not having any episodes of rejection	(This meaning unit coincides with 11.9)
		12. He feels satisfied by the total success of the transplant	11.10 Successful HT allows the recipient to return to normal life.
		13. He feels happy for the privilege of feeling well	
		14. He recovered the capacity to do daily activities.	

HT – heart transplant

RESULTS

The convergences of the interviews were grouped in three categories that describe the phenomenon “the experience of undergoing heart transplantation”: the heart transplantation, interpersonal relationships and reflection about the experience of undergoing heart transplantation.

The heart transplantation

Coming to terms with the inevitable

All participants were suffering end-stage heart failure at the time they were told that transplantation was the only option. For some it was the end of uncertainty and a hope; for others, feelings of insecurity and fear. All were aware that it would not be a choice, but the only chance of life:

Table 3. Categories that emerged from the interviews with 26 heart recipients to the question "How do you yourself see the experience of undergoing heart transplantation?"

The HT process	Reflection about the experience	
	Interpersonal relationships	To have a heart transplanted
Why HT	the donor	Evaluating the meaning of HT
Heart disease symptoms	the professionals	evaluation of the transformations
the necessity of HT	the family	the work
decision to transplant	colleagues	self-awareness
Waiting for the HT	religion	
The surgery		
Life after HT		

HT – heart transplant

“The doctor said ‘do you have children? Do you want to bring up your children? It is the last chance you have, transplantation.’ – I thought and I agreed.” (P7)

On accepting the transplantation, there is a long wait, non-compatible donors, events that force patients to leave the waiting list. One recipient said: “In January, I was taken off the waiting list because I had some small problems. In February, I returned to the list. When you start this process of entering and being taken out of the waiting list ... it is very hard as the disease continues ... it is as if you, God! You have the chance to do transplantation, but at the same time, will there be enough time? Will the time be enough? The waiting list is so long, the wait is long, all this makes you apprehensive.” (P9)

For many, the history of transplantation is a victorious story: good results follow difficult periods, complete recovery and return to the normal life. Others describe the complicated post-operative period, with periods of rejection, infection, returns to hospital and other operations: “I went home, two months after I felt bad. New examinations were made that showed that I needed lung surgery, I had an abscess. One third of my lung was removed. I improved, on the eve of being released from hospital for the second time and I caught a hospital infection. I stayed almost 50 days in eight months. After, I started to feel better.” (P16)

After transplantation life is transformed. Recipients start to breath, eat, drink water, move about, work, etc. However there are restrictions that are difficult to comply with: “When I feel a desire to eat a particular type of food ... for example feijoada, I go there and take a little, eat a little. It is not

that it will be bad for me. I do not believe it will be bad for me. Of course, it would be bad for me if I eat a feijoada every week.” (P1)

Living with the other health problems such as rejection and adaptation to medications:

“After four years I have had to do saphenous and mammary grafts. I think that the medication, cholesterol, high triglycerides, and so I had to do saphenous and mammary grafts. In 1999 an angioplasty. I think ... how should I put it, I am on overtime (laughs).” (P1)

“This rejection, summed to the toxic reaction of cyclosporin, caused renal injury and I started hemodialysis for one year. And now I am feeling better, I am on the waiting list for kidney transplantation.” (P20)

Despite of the complications and limitations, life can be normal:

“Today I do everything. I work normally in my house, collect my son from school, go to bed at midnight, half past midnight. My husband works late and arrives home late...” (P7)

“After, I did not feel anything anymore. We also feel... normal diseases, flu, a fever, stress, but this is normal for everyone isn't it?” (P13)

Interpersonal relationships

Relationships are developed with the people with who the experience of HT is shared. The donor is remembered as a central figure: “From the moment that you have a donor, when you accept to do the transplantation, you start to see

the light at the end of the tunnel. Your life starts to change." (P11) Some patients express the desire to thank the donor family. Apart from gratitude, there are ambiguous feelings:

"Before operating, it is like this...a feeling of guilt, I don't know. There was a day that I asked Dr. Y: "I was thinking that, to survive, a person has to die. It is something a little strange that we feel." He said: 'No you should not think of this. You have to think that you can cross the road here, today, and die. I am a donor. And so, if I die, what I can give to a person, I will give. And so, accidents always happen. You can not think like this. You have to be a little egoistic. Think about yourself, because you depend on this to survive.' And so I calmed down a little." (P2)

Doctors and nurses are a part of this experience. Apart from the dependence, patients have feelings of gratitude and affection for them.

"I think I need to thank the doctors, thank all the team that took care of me, they were very good. Dr. Z, who performed the surgery, the doctors who accompany me until today. I feel well looked after here, you know?" This for me is very important. Here is like an extension of my own home." (P5)

"In relation to treatment and hospital, the doctors, everything is marvelous, the nurses... Not all mothers treat us as well as the nurses in this hospital, there are mothers who abandon us and the nurses welcome us so well." (P12)

The families are co-protagonists in the story. The spouse is present, encouraging, helping to understand what is happening. The children represent a stimulus in the struggle.

Patients meet strangers in similar situations. They give support and the support is repaid:

"When I was in the hospital bed, Dr. Y asked some patients to speak with me because I was very calm, everything had turned out well. People who are waiting for transplantation are afraid...they are always petrified. I talked with them, trying to transmit sincerity, calm, tranquility and...and trying not to be tense, nervous. When you have a problem, if you are nervous it is worse." (P15)

Develop awareness about the necessity to educate the people in relation to HT: Recipients report their participation in campaigns to encourage organ donation. One of them gave a critical view:

"It would be good if people would become more aware, with these organ donation campaigns. I made a statement in Incor. It is funny that in our country it is necessary for a famous person to appear on television, to be transplanted, for the people to realize that organ transplantation is so necessary. It seems to be just a moment and after, everything is quiet again." (P26)

When there are no perspectives, we resort to faith. God, for some, is responsible for everything that happens:

"God allowed me to continue living, put me in the hands

of Dr. X, to make the transplantation. I was disillusioned. My family, the church I go to, everyone started praying for this. There was no donor...and then one appeared. The donor has come, it seemed it was to order because he came with the same weight as me, same height, same rib cage...the weight, blood...of him were the same as mine." (P14)

Reflection on the experience of undergoing heart transplantation

Participants, on analyzing what the experience of HT means to their existence, talk about the exchange of hearts, about the transformations that they were submitted to, their self awareness and their reality.

Heart transplantation signified, for all, a new chance of life – a rebirth. One participant described: *"When I awoke from that surgery, it was as if you realize what it is to be reborn. It is as if you are free from all those problems, you will restart all again. It was like this that I felt."* (P9)

Get back autonomy and transform the manner of perceiving it:

"I felt bad because I could not do what I wanted. Today I feel well, doing what I couldn't. Thank God. I look after my children... Before I did not go to parent teacher meetings..." (P7)

Recover the perspective for the future and the continuation of life:

"The best thing was that I returned to my studies which I could do before, I could not remain in the classroom. Now, no, I go, back to normal. The year that I lost I managed to recover in the 8th grade, I did the 8th and 9th together." (P21)

Rediscover the authentic significance of life:

"You, God! You start to live again. Do you understand? You do not vegetate any more, you live. Every moment, every day you wake up, you thank God for being alive. And each night when you lie down to sleep, you thank God for another day." (P1)

The majority of the recipients believe they recovered their health; now they are normal people:

"Today I drive, I work, I do everything, I walk alone, I eat anything, and I feel very well. It has been almost five years and I am like I was before I had heart disease, 100% healthy." (P16)

"And after they say that it will not be rejected anymore. My life, I do not know... was improving day by day, now I am very healthy, I am a normal person." (P22)

The possibility of returning to work means retaking your position:

"Many people at that time said: 'You can retire because you transplanted.' But I did not want to, I continued working. I work until today." (P4) . Some perceive discrimination:

"Even a healthy person has difficulty in finding a job. A sick person... that is, transplanted is more complicated." (P12)

Some recipients talked about the exchange of hearts:

"In respect to the heart, for me it is as if I never transplanted. I say this because: I do not feel anything, for me it is mine that is there, do you understand?" (P1)

"Remove the heart from a guy and put it in me. It did not give any problems...none. Impressive! I find it hard to believe. Everyone jokes saying 'God! Now you are 51 years old but like an 18-year-old!' (laughs) Today I am 22 years old, aren't I? When I have lived another 50 years, I will be one hundred years old or so!" (P11)

One recipient, after four years, still resents the loss of his heart: *"I will always remember that, that I live today...do not live with my own heart. Never more will it be the same thing."* (P8)

Recently transplanted, a patient speaks of his conflicts and anxieties:

"I thought, but this heart, and now I will go so far away; it is such an individual specialty nowadays; few places with assistance. And I will go to the interior of the country, 4000 km away. I started thinking: 'And now?' I was so happy, a contentment that does not have words either. And so it was very good. And these thoughts have repeated. These thoughts are repeated constantly. Today I only think about this more vaguely, rarely. I already accepted that it was really a privilege. Today I think about this much less." (P25)

Others report how they deal with anxiety, trying to overcome it:

"I think that people when they are waiting, the people need to forget that they are going to do a transplantation, you know... Go there, do the transplant, and they will not realize that transplantation was performed on them." (P1)

"After the operation when I returned to normal, I felt the heart beating. I said to my doctor: 'it is strange', because before I did not feel it. And so the heart was strong, beating. He said: 'Forget about it.' And so I got used to it again. Knowing that everything was returning to normal." (P3)

"As I said, I lived my life, I do not try to remember. I think that we have to forget the bad things of life. Although it was hard, specifically in the postoperative period, that we even almost lose it sometimes, because I passed a really bad time, you know?" (P26)

An adolescent transplanted at eight years old, values what he thought he had lost:

"I am living the childhood that I lost, nine lost years. I grew up, developed. I was not tall, I was 1.2 meters. And so, for me, it was a stage that I could live through. The most important thing was this." (P21)

DISCUSSION

The findings of this study are consistent with previous publications in respect to the effectiveness of transplantation to treat symptoms of end-stage heart failure [2,3,9,11] and in respect to rejection and episodes of infection, which still constitute the greatest cause of morbidity and mortality in the immediate postoperative period [17]. Results of patients operated in Brazil show a 5-year survival of 50% for transplanted patients, 10% lower than the corresponding rates from the USA [18,19].

In relation to the quality of life of recipients, our data are similar to national and international publications: there are improvements in relation to the physical symptoms and the general well-being is recovered, although the psychosocial and economic factors depend on the patients' conditions [2,3,5,8,9]. Recipients return to their normal activities and have a possibility to plan for the future, which before was impossible. However, there is lack of satisfaction in respect to the social life and financial situation and oscillations in the emotional condition in some periods [5,9,12,20,21]. Kuhn et al. [20] considered that 'distress' is present in all stages of the heart transplantation process. Dobbels et al. [22] analyzed the persistence of depressive symptoms and difficulty of patients to overcome problems five to ten years after transplantation. One of the concerns expressed by several participants in the current study was concerned with difficulties to return to work, which is mentioned in the studies of Paris & White-Williams [5] and Kaba [14] as one of the most serious social problems encountered by heart recipients.

The difficulty to accept organ exchange expressed by some participants is commented by Kaba et al. [13] and Inspector et al. [22] on analyzing conflict of recipients faced with the loss of their own hearts with all the symbolism that this organ carries; and the acceptance of the donor heart, which was only possible because of death. Inspector et al. [22] and Trifaux et al. [23] concluded that people submitted to HT present with magical and unbelievable thoughts in respect to the organ due to the symbolic significance of the heart and the stress during the whole post-transplantation process. According to Trifaux et al. [23] the transformations that occur in this process, as a whole, lead to the recipient perceiving the uncertainty of human existence simultaneous to the emergence of satisfaction of having a new chance to live, valorizing, in particular, affective relationships. Kaba et al. [13] identified the ways in which patients cope with the post-transplantation stress: from exaggerated optimism to negation of the seriousness of the situation; and some positive forms of returning to reality by resorting to outside help.

The data of the current study are similar to findings of the aforementioned studies: the participants were satisfied

and valorized the results of HT, even those who still presented with rejection and other complications. In relation to this, Dew & Switzer [24] reported that this satisfaction, in spite of the difficulties faced, is due to the notion that they received a valuable present: an extension of life that had been lost. Contrary to the perception of the participants of this study, Evangelista et al. [12] compared the quality of life achieved after HT with the quality achieved with other procedures (pacemaker implantation or stabilization by medications of heart failure symptoms) and concluded that the quality of life post transplantation was less than healthy individuals.

Using the phenomenologic approach, the data of this study demonstrated meanings of the HT experience not shown by the quantitative studies mentioned in this article:

- Living in the universe of end-stage heart failure, the participants inverted the contingency of being launched into the fatality of HT – the only way out from their extreme physical suffering and to stop the anguish of imminent death. This living situation that, for many had been a long time before, is still present in all interviews. How it still influences their way of life in the current setting.
- After exchanging hearts, the feelings of suffering and insecurity persist, causing a constant anxiety: after the complex surgery, the immunosuppressant therapy and its harmful effects; the necessity to rigorously follow a diet and the changes in the style of life, always depending on the hospital and the healthcare staff. The struggle will never finish.
- Being aware of this extreme dependence and of the still existent risks; facing changes, perhaps new interventions, perhaps new transplants; even so feelings of happiness predominate, all celebrate being alive. And learn to recognize the essentials of existence.

These studies reveal how complex and contradictory the process is. Frequently it seems ambiguous: to wait for transplantation means suffering and uncertainty, but it is a privilege to find a donor – although feeling guilty for the death of the donor; the transplanted heart signifies life and recovering physical autonomy, but also means dependence on a treatment that lasts forever, and even more suffering, and even more struggling. The future is uncertain, there is a future.

The ambiguity of this reality clearly shows data on recipients in respect to notions of having health and leading a normal life as normal people. Even for those who continue to have severe complications after transplantation: two of the participants run the risk of requiring renal transplantation due to these complications. Corbin [25] reported that, in the view of people in general, to have health means the absence of strange sensations, pain or discomfort; to overcome the symptoms of disease, the body, that becomes 'non-familiar'

during the illness, returns to being familiar. Thus, the patients feel cured on re-acquiring control over their lives and over their bodies, returning to normal activities, even when they continue to be submitted to treatment for chronic diseases. These conceptions about health give us an existential feeling of the body in the sense described by Merleau Ponty [16]: I am my body, it is my anchor to the world. And it is through my body that I live, act, interact with the surrounding world. Thus, it is possible to understand that the participants, on saying that they reacquired health and normality in life with the new heart, are explaining how they returned to act, interact, appear and to live how they used to live before the heart disease. The study of Wise [15] on children and adolescents after liver transplantation, shows that the main concern of these young people is to be similar to their colleagues: they struggle to feel and be seen as 'normal'; which was impossible before transplantation. The interviews of four adolescents, participants in the current study, shows the same idea of being 'healthy' and 'normal' which was made possible by HT.

The results found suggest that, in all phases of HT, the role of professionals together with the recipient is crucial, both as support to overcome the anxiety and insecurity, as for educative actions in respect to the interventions and guidance during the whole process. The feeling of optimism, which predominated among the participants, probably favors compliance to treatment. Or perhaps signifies a barrier to this adhesion, if the recipient is unaware of the real conditions and limitations. Thus, the expression of the recipient about his subjective experience arises as an essential datum, which should be the basis for his care program.

Another essential result is in respect to members of the recipients' family. Perceived by the participants as the motive to continue the struggle and as partners in all the process, their importance as support to the patients has been recognized by healthcare professionals [5,8]. However, they are not always included in the educative process destined to the recipients and are not always contemplated in support interventions in relation to anxiety and suffering that they face on accompanying their relatives. One participant of the study requested that the support, which was so effective for him, should be extended to his relatives.

Thus, there is an important challenge for professionals who work with recipients, which is to help individuals submitted to HT and their relatives to be responsible for self-care: stimulating the patients with the entire support team to have their own autonomy.

CLOSING COMMENTS

This study did not propose generalizations but to describe the studied phenomenon from the view of the

participants, contextualizing in space and time where the study was developed. The findings of the study identified new questions to be investigated: compliance to treatment after HT; the relationship between family and donor; the family of the recipient and their role in the HT process; work and adaptation to transformations after HT; the actions of nurses and doctors, and other professionals in the team to support recipients.

We consider that this qualitative study gives a possibility to identify the private universe of each patient; to allow an understanding of individual difficulties and needs. A better comprehension in the way the recipients live through this process, with their possibilities and limitations, is essential to develop interventions guaranteeing that all fully achieve the benefits, in the context of heart transplantation and its continuous evolution.

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COMMENT

“When you opted for the phenomenological method, discovering with intersubjectivity, I thought that its concept

could make the approach more wide-ranging, probably using the Heidegger notion to make the subject clearer. We know that this philosopher, who learnt with Husserl, saw in phenomenology a way of revealing what was occult, without plainly showing it. “What is evident, shows that which is not evident” (Heidegger) revealing exactly the synthesis between the essence (that which remains hidden) and the existence (that which is concretely seen, as an expression of the phenomenon).

As this is not a scientific investigational method, at least in respect to the idea of objectivity in research, it is necessary to understand that what is revealed is the essence, without it becoming directly accessible to our senses but, even so, it is not less true: as in the case of fever (phenomenon that is manifested) revealing the infection (essence, that remains concealed).”

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